Abstract

Background: The chapter evaluates the evidence for the inclusion of patient narratives in patient decision aids (PtDAs). We define patient narratives as stories, testimonials, or anecdotes that provide illustrative examples of the experiences of others that are relevant to the decision at hand (1).

Method: To evaluate the evidence for the effectiveness of narratives in PtDAs, we conducted a narrative scoping review of the literature from January~~,~~ 2013 through June~~,~~ 2019 to identify relevant literature published since the last IPDAS update in 2013. We considered research articles that examined the impact of narratives on relevant outcomes or described relevant theoretical mechanisms.

Results: The majority of the empirical work on narratives did not measure concepts that are typically found in the PtDA literature (e.g. decisional conflict). Yet, a few themes emerged from our review that can be applied to the PtDA context including the impact of narratives on relevant outcomes (knowledge ~~(e.g. task-specific, either medical or non-medical)~~, behavior change, and psychological constructs~~)~~ ~~(e.g. emotions, perspective taking)~~ as well as several theoretical mechanisms about how and why narratives work that can be applied to the PtDA context.

Conclusion: Based on this evidence update, we suggest that there may be situations where narratives could enhance the effectiveness of patient decision aids. The recent theoretical work on narratives has underscored the fact that narratives are a multi-faceted construct and should no longer be considered as a binary option (include narratives or not). However, the bottom line is that, given the heterogeneity that exists among stories, the evidence does not support a strong recommendation for narratives to be a required element of PtDAs.

Background

Definition of quality dimension

The chapter evaluates the evidence for the inclusion of patient narratives in patient decision aids (PtDAs). PtDAs are resources that draw on evidence from the decision sciences to support people's decisions about treatment, screening, or testing options in accordance with their own values (2). PtDAs follow guidance to ensure their structure and content describes the health problem, makes explicit the decision problem, provides an accurate and balanced description of all options and their consequences using accessible language and figures, help patients evaluate these facts, and provide guidance to help make trade-offs between options (1, 3). Many PtDA developers also use patient narratives to enhance the content and delivery of the material (4-6). We define patient narratives as stories, testimonials, or anecdotes that provide illustrative examples of the experiences of others that are relevant to the decision at hand (1). Narratives can be produced in many forms (e.g. written, audio, or video). The purpose of this chapter is to summarize evidence for the effective use of patient narratives in PtDAs. Specifically, we will evaluate whether there is sufficient evidence to recommend that PtDA developers include patient narratives to enhance the effectiveness of PtDAs.

Theoretical rationale

The primary theoretical rationales for the inclusion of narratives in PtDAs are to engage the audience and provide information about the patient experience. In the broader literature on narratives, there is evidence that narratives may achieve both of these goals when compared with standard information. In a recent review, narratives have been shown to have two primary functions (7). First, narratives have been demonstrated to communicate information more effectively than didactic information because narratives: 1) tend to be more engaging (e.g., 8, 9), 2) result in better recall (e.g., 10), and 3) generate fewer counterarguments to the message (e.g., 11). However, narratives also have

been shown to change attitudes, judgments, and behaviors (1, 7, 12). A primary challenge for PtDAs is to include narratives to further support people's reasoning, without impacting judgment (1, 13).

Theoretical and empirical work in cognitive and social psychology has demonstrated that narratives can be more persuasive than didactic information (1, 7, 12), and several studies in decision making have shown that narratives can alter preferences for medical treatment (e.g., 14, 15, 16). Further, health professionals often express concerns over the use of narratives in PtDAs because the stories themselves are not subjected to scientific scrutiny (13), and as such provide an opportunity to pass on misinformation. Some research has demonstrated that people do not adjust the weight they give to narrative information based on source credibility (i.e., narratives from an anti-vaccination website vs. narratives from a neutral news website) (17). Finally, when narratives are presented in conjunction with statistical information, narratives can overshadow the data leading people to ignore data and overweight stories in their judgments of risk (e.g., 18).

Method

To evaluate the evidence for the effectiveness of narratives in PtDAs, we conducted a narrative scoping review of the literature from January 2013 through June 2019 to identify relevant literature published since the last IPDAS update in 2013. We considered research articles that either examined the impact of narratives on relevant outcomes (e.g., knowledge, behavior change) or described relevant theoretical mechanisms about how and why narratives work. Several recent systematic and narrative reviews demonstrate the vast majority of research on narratives conducted since the 2013 chapter was outside the context of PtDAs (e.g., 7, 19). This scoping review methodology is more flexible than a systematic review, and enables the update to be informed by a wider literature of relevance to understanding the role of narratives within PtDAs (20, 21). Accordingly, we broadened the fields of study beyond the specific context of PtDAs to include articles about the use of narratives in both health-

related and non-health related contexts (e.g., Communication, Journalism). An *a priori* proposal of these methods was reviewed and approved by the IPDAS Steering Committee.

All members of the research team, who are all co-authors on this update, participated in the process of identifying relevant studies for inclusion in the scoping review. Each member of the research team was asked to identify important articles for inclusion across three categories: 1) Narrative research in the context of patient decisions aids or patient decision making; 2) Narrative research in the field of healthcare more broadly; and 3) Narrative research in other non-health related fields. Articles were identified through searches of relevant databases (PubMed, Google Scholar, Web of Science, PsychInfo, and PlosOne) using search terms such as "patient narratives", "personal narrative", "patient testimonials" alone and in conjunction with "decision making". The research team also mined potential studies from recent publications and through our respective networks of colleagues. We focused on articles that were published after the last IPDAS update was written (i.e., since 2012). We maintained a shared research drive where the research team uploaded copies of potential articles into folders demarcating each of the three categories described above. The research team cataloged the articles into a shared database, which was coded according to these categories.

We identified 170 new articles for the scoping review, with only 44 of these manuscripts loosely defined as PtDA-relevant contexts (i.e., research was done in the context of a patient decision aid or patient decision making more generally). Of the remaining 126 articles, 99 addressed issues about narratives in other health-related contexts, while 27 articles were about narratives in non-health related contexts. A recent Cochrane Review on the effectiveness of PtDAs demonstrated that these tools have been shown to increase patient knowledge, reduce decisional conflict, decrease the number of patients who are undecided about the appropriate treatment for themselves, and improve the match between patient values and their choices (2). The largest challenge in mapping the findings of the diverse body of work identified in our review onto our objective—evaluating whether patient stories

enhance the effectiveness of PtDAs—is that the majority of the empirical work on narratives did not measure concepts that are typically found in the PtDA literature (e.g., decisional conflict). However, a few themes emerged from our review that can be applied to the PtDA context including the impact of narratives on knowledge (e.g., task specific, either medical or non-medical), behavior change, and psychological constructs (e.g., emotions, perspective taking).

To summarize the data, each member of research team was assigned approximately 20 articles to read, create a short, written summary of the information in the article relevant to our objective, and provide key words organizing the articles topically. To collate the findings, the first author created a preliminary draft of the manuscript based on the themes identified in the review and the summaries written by all the co-authors. The draft was circulated to all of the co-authors for discussion, editing, and refinement. The largest area of debate was concerning the extent to which we would address the modality of narrative delivery (i.e., video vs. text). Given the question was tangential to our overall objective, the chapter leads opted for a higher-level discussion of this topic. The feedback from the research team was incorporated into a revised draft by the first author, which was sent to the team for final review before the manuscript was submitted.

Results

Knowledge

Several studies demonstrated that narratives were an effective method of increasing knowledge in both health and non-health related contexts compared with usual communications, while a recent systematic review did not find evidence for knowledge gains with narratives in computer-based decision aids.

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Murphy and colleagues reported that narratives were more effective at increasing cervical cancer-related knowledge than non-narrative health communication interventions in a Latina population (22), and Moran and colleagues reported that the narrative health education film produced greater HPV- related knowledge gains than a non-narrative film (23). Alteren argued that narratives were useful in the development of knowledge in clinical training (24). This was consistent with the work of Kilaru and colleagues that compared the ability of an evidence-based narrative and a traditional summary to increase recall of opioid prescribing guidelines (25). Total recall was significantly greater in the narrative arm than in the summary arm. However, some themes were better recalled by the summary arm and some themes were better recalled by the narrative arm. In addition, there was a significantly greater number of extraneous or false pieces of information recalled in the summary arm than the narrative arm. Despite the fact that a number of articles have demonstrated that narratives are an effective method of increasing knowledge, a recent subgroup analysis from a systematic review of computer-based PtDAs reported that inclusion of patient narratives (patient stories and behavior modeling) in these tools (7 studies) compared to computer-based PtDAs without patient narratives (11 studies) did not have a significant effect on knowledge acquisition (5). Finally, research conducted by the National Bureau of Economic Research compared the effect of different education program formats (informational brochure, interactive visual tool, written narrative, and video narrative) on financial literacy, measuring knowledge, confidence, and self-efficacy (26). All formats successfully increased financial knowledge, confidence, and self-efficacy relative to the control group, which did not receive any intervention.

Attitudes, Persuasion, and Behavior Change

Several systematic reviews have addressed the ability of narrative messaging to affect behavioral intentions and behavior change. A number of studies reported positive effects of narratives. For example, in their review, Perrier and colleagues reported that narrative interventions significantly

increased intentions to engage in cancer screening; however, there was also inconsistent evidence about whether narratives produce greater change in intentions to screen compared with statistical interventions (27). In a second systematic review, Perrier and colleagues demonstrated that narrative messages enhance health-promoting behaviors, but again evidence was mixed as to whether the effect size associated with narrative messages was larger than statistical messages in the promotion of behavior change (28). Braddock and Dillard conducted a meta-analysis of 74 studies, which included over 7,000 participants and determined that narratives can move beliefs, attitudes, intentions, and behaviors towards the viewpoints expressed in the narrative (29). Finally, a review by Shen, Sheer, and Li indicated that narratives demonstrated a small but significant effect on persuasion outcomes, with a slightly larger effect size for behavioral outcomes when compared with attitudes or intentions (30). This pattern of findings is also observed in several recent studies indicating that narratives were more effective than non-narrative messaging at promoting dietary changes (31), increasing vaccination intentions (when presented in conjunction with statistical information) (32, 33), increasing intentions to be screened for colorectal cancer (34, 35), and increasing self-efficacy and self-care behavior in patients with Type II diabetes (36).

Several studies also report a significant negative effect of narratives on attitudes, intentions, and behaviors. For example, Shaffer and colleagues assessed a narrative in a health-news story about a woman who had a severe allergic reaction to an over-the-counter medication (37). Exposure to the narrative resulted in significantly less use of the medication over the following two weeks in comparison to at baseline and intentions to use the medication in the future remained lower than baseline. Similarly, Scherer and colleagues reported that providing participants with narratives submitted to the Vaccine Adverse Events Reporting System actually decreased acceptance of the HPV vaccine despite the fact that the stories were not particularly plausible (38). Witteman and colleagues examined the impact of polarizing social media comments on intentions and attitudes towards home births (39).

Comments with one-sided opinions influenced participants' attitudes towards home birth, particularly if the comments included personal stories. Additionally, negative personal stories were particularly salient. However, when the comments reflected multiple perspectives on home birth (i.e. NOT one-sided opinions) attitudes and intentions were not affected. Finally, a manuscript by Arkes and Gaissmaier identified the power of anecdotal information in driving the backlash against the PSA screening recommendations provided by the United States Preventive Services Task Force (USPSTF) (40). They argue that the public dialogue surrounding cancer screening is replete with stories of people who believe their lives have been saved by screening and early detection despite epidemiological data to the contrary. The use of stories in response to the statistical information used by the USPSTF to justify their recommendation demonstrates the potentially persuasive power of even a single narrative over an army of statistical data.

A third group of studies report no effect of narrative messages on a wide variety of health behaviors including uptake of routine cancer screening services (41), carrier screening tests (42), online cognitive-behavioral therapy intervention for depression (43), and preferences for treatment in a hypothetical cancer scenario (44). McGregor and colleagues observed no differences in cancer screening uptake when a narrative was included in a screening invitation letter (45), and Nyhan and colleagues found that narratives (along with other informational interventions) were not effective at increasing parental intent to vaccinate a future child (46).

Psychological Constructs

Several articles examined the effect of narratives on a wide variety of psychological constructs. Bollinger and Kreuter reported more positive emotional responses to narrative videos than informational videos about breast cancer for African American women (47). Participants reviewing the narrative video were more likely to report feeling attentive, inspired, and proud, and less likely to feel upset. Narrative interventions were also associated with increasing empathy (48), emotional

identification (22, 49, 50), and perspective taking (51, 52). Further, narratives have been associated with minimizing affective forecasting errors (53) and creating a more positive attitude towards stigmatized health behaviors (54, 55). However, Syrowatka and colleagues reported that decisional conflict increased following the use of computer-based PtDAs that included patient stories (broadly including both narratives and behavior modeling) compared with computer-based PtDAs without patient stories (5).

In addition, narratives may play key roles in "finding information, feeling supported, maintaining relationships with others, affecting behavior…experiencing health services…learning to tell the story, and visualizing the disease" (56). Ziebland and Wyke also argue that 'learning to tell the story' and 'visualizing the disease' domains are important features that have been under-acknowledged so far in research (56). Narratives are also well suited to conveying emotion, explaining logic, providing relational information, and capturing naturalistic experiences (57). They may be a particularly effective tool when health communicators are trying to help patients avoid surprise and regret, recognize dominant options (e.g., smoking cessation), motivate to act or not act, and make multi-attribute tradeoff decisions. Narratives may also be helpful in communicating evidence from systematic reviews and improve stakeholder engagement (58).

Narrative Theory

The IPDAS update 2013 suggested that some types of narratives may be more appropriate to include within PtDAs than others, with Shaffer and Zikmund-Fisher providing a taxonomy of narrative types: 1) Narrative Purpose (inform, engage, model behavior, persuade, and comfort); 2) Narrative Content (process narratives, experience narratives, and outcome narratives); and 3) Evaluative Valence (positive and negative narratives) (7, 59). Subsequent work found that process narratives (i.e., stories that focused on *how* patients made a particular decision) increased time spent searching for information in a patient decision aid for early-stage breast cancer, and experience narratives (i.e.,

what it is like to have a disease or treatment) increased confidence in the hypothetical decision and a greater sense of feeling informed (60). Gavaruzzi and colleagues (61) and Graaf, Sanders, and Hoeken (62) reported that different types of emotion-laden narratives can have different effects on behavior, and Witteman and colleagues reported that negative birth stories were more influential than positive birth stories in the development of attitudes towards home birth (39). On the other hand, a relief-based narrative (i.e., describes relief from a negative test result) was more effective in promoting intentions to screen than a regret-based narrative in the context of colorectal cancer screening (61). Other work demonstrated that narratives from a positive role model who focused on healthy behaviors were more persuasive than narratives from a negative role model who focused on unhealthy behaviors (62, 63).

These typologies are important because the specific narrative content is also likely to be an important determinant of narrative impact. For example, Scherer and colleagues tested the effect of four narrative messaging conditions on interest in Prostate-Specific Antigen screening: 1) physical harm narrative, 2) emotional harm narrative, 3) overdiagnosis narrative, or 4) all three narratives together (64). The physical harm narrative was the only narrative to significantly decrease intentions to be screened for prostate cancer. Keer, van den Putte, de Wit, & Neijens reported that narratives were more effective at discouraging binge drinking in college students when they contained affective arguments, designed to address emotional consequences of decision making, than when they contained instrumental arguments, designed to address the logical consequences of decision making (65). The authors argued that the instrumental content reduced the efficacy of the narratives because they prevented the audience from being transported into the story. This represents a key theoretical development in understanding the process by which a given narrative has its impact. Narrative effects are moderated by the degree to which message recipients are *transported* by the content of the message (66). Narrative Transportation Theory (e.g. 67) describes the extent to which individuals

become completely psychologically engaged in the narrative. In support of this hypothesis, Dillard and colleagues reported that transportation from a narrative health communication message designed to reduce skin cancer risk was positively associated with behavioral intentions (e.g., engage in skin self-exam, talk to doctor, reduce UV exposure) (66).

More recently, researchers have explored transportation as a key mechanism for the effect of narratives on people's judgements and behavior. In the Narrative Immersion Model, Shaffer and colleagues describe the specific impact (e.g., type and magnitude of the effect) of a particular narrative by identifying narrative types and characteristics of narratives that are likely to increase their impact (7). Van Laer, De Ruyter, Visconti, and Wetzels conducted a meta-analysis on narratives to identify the antecedents and consequences of narrative transportation from a multidisciplinary literature, resulting in the development of the Extended Transportation Imagery Model (19). Narratives promoting increased transportation included: 1) characters with whom the audience can identify; 2) an imaginable plot; and 3) verisimilitude (i.e. the perception or appearance of being real). Dillard and Main also examined the moderating effects of vividness and perceived similarity in narrative messaging and reported that greater vividness (and to a lesser degree, greater identification with the narrative) was associated with increased knowledge about colorectal cancer screening and intentions to be screened for colorectal cancer (68). There also are a number of additional structural features of narratives that impact their persuasive ability (69), including format, with audio-visual narratives having greater persuasive ability than text-based narratives (30, 26, 71).

Research also has pointed to a number of audience characteristics that interact with messaging content to impact message effectiveness. For example, the meta-analyses conducted by Van Laer and colleagues concluded that message recipients who are more likely to be transported are generally: 1) familiar with the story topic; 2) pay attention to the story; 3) are transportable (i.e., high scores on this individual difference measure); 4) young; 5) educated; and 6) female (19). First person narratives

are often found to be more persuasive than third person narratives (33, 63). Additionally, there are individual differences in the impact of narrative messaging. For example, Scherer and colleagues reported that the response to didactic and narrative information was strongly related to participants' minimizing or maximizing preferences for healthcare (64), with medical maximizers (i.e., patients who tend to prefer active over passive medical treatment) being significantly less effected by the didactic and narrative health communications than were medical minimizers.

Discussion

The objective of this review was to evaluate the evidence for the inclusion of patient narratives in patient decision aids. As few studies systematically evaluated narratives and PtDA effectiveness since the last review (1), we used a scoping method to capture research investigating narratives and their impact on health-related decisions more broadly. The pattern of results observed in this update was similar to the findings reported in the 2013 IPDAS update. In some studies, narratives increased people's adherence or uptake behaviors (i.e. were persuasive) and enhanced knowledge (e.g., 25), affective forecasting judgments (e.g., 53), and empathy (48) (i.e., were supportive), while narratives had no effect in other studies (e.g., 27, 28). It is unclear why some studies had null findings while other studies did not because the narratives and their audiences were fairly heterogenous. Researchers are beginning to unpack characteristics of the narrative and the recipient that may help to better understand when narratives are effective and for whom they have an effect. It may be that some stories will never simply have a significant effect because they did not include specific story features (e.g., authenticity), or their effects were not adequately measured. However, on the whole, recent systematic reviews have shown that narratives are an effective tool for persuasion, although their superiority to statistical messaging has not been sufficiently established (e.g., 28, 29). Narratives are also generally effective at increasing knowledge (e.g., 25) and have a number of psychological benefits have recently been documented including the potential to improve affective forecasting (e.g., 53) and increase

empathy (e.g., 48).

Conclusions about whether narratives are a recommended component of decision aids are strongly tied to beliefs about the nature of what PtDAs are designed to accomplish. Some researchers view PtDAs only as tools designed for decisions that are "preference sensitive". A decision is considered preference sensitive when there are at least two valid alternative treatment strategies for most patients (72) and the choice between the treatment options depends upon how patients value the benefits versus the harms (73). In this context, decision aids are designed to provide a balanced presentation of information and persuasion would be viewed as an undesired consequence of the inclusion of narratives. However, PtDAs have increasingly been used for decisions outside this narrow context, including health contexts where an "effective" treatment exists—i.e., where one treatment option is dominant, with greatest benefits and least harms (72)—such as vaccination uptake (74, 75). In fact, there is a growing call for the use of PtDAs to facilitate the uptake of clinical practice guidelines (e.g., 76). In contexts where the evidence in favor of one treatment option is superior (e.g., smoking cessation), narratives may be viewed as a desirable component of decision support when the goal to promote informed decision making outweighs the desire to present balanced options.

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Our research team had varying opinions about the value of narratives and the role they should play in PtDAs. However, our final recommendation was reached with consensus. The goal of this review was to make a recommendation about whether patient stories should be a required component of PtDA by reviewing the current evidence regarding their effectiveness, and we have concluded that the literature does not support such a recommendation. Our conclusion is based on two points identified in this review. First, although there may be situations where narratives could enhance the effectiveness of patient decision aids, we have also documented several situations in which narratives produce responses, such as bias and persuasion, that run counter to the intended purposes of PtDAs. Because of these findings, we concluded that we cannot provide a blanket recommendation for the inclusion of all types of patient stories. Recent theoretical work on narratives has underscored the fact that narratives are a multi-faceted construct and should no longer be evaluated in a unidimensional framework. Moving forward, the more appropriate question is whether there are types of patient narratives that might be more appropriate for some PtDAs than others (13). For example, outcome narratives designed to be persuasive may not be appropriate for a patient decision aid designed to support decisions in the context of clinical equipoise, whereas process and experience narratives designed to engage, inform, and comfort could contribute to the stated goals of a PtDA (7).

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A second consideration in the development of our recommendation was the fact that we identified a number of practical challenges to developing narratives for inclusion within PtDAs. The development of compelling stories requires a rigorous elicitation process, and a number of important editorial choices must be made along the way, including which stakeholder voices to include and whether or not quotes are used verbatim or are edited (77, 78). PtDA developers must also address several issues including a) which component of the IPDAS checklist the story is enhancing, b) how stories should be systematically and ethically elicited, edited and compiled, and c) which points of view, conflict, resolution, and structure should be chosen (78). With the growing prevalence of mHealth, computerized, app and internet-based decision aids, developers of PtDAs should also consider the preferred format for inclusion of narratives as well as the type of patients and/or potential end-users (e.g., 71). Developers looking to include narratives in healthcare communications and PtDAs need to be mindful of the process used to elicit narratives to ensure they achieve the developers' goal with no unintended consequences on judgments and behaviors. PtDA developers should rely on qualitative methods to identify all the needs of stakeholders and to capture a full description of the health problem, decision problem and consequences on daily life as well as illness for all options. In sum, we have concluded that the literature does not support a recommendation for narratives to be a required element of PtDAs largely because of the heterogeneity in the effects of patient stories and the subjective nature of their elicitation process.

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